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Understanding the treatment preferences of people with relapsing remitting multiple sclerosis

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Background: The last decade has seen a large increase in the number of disease modifying treatments (DMTs) for people with relapsing remitting multiple sclerosis (PwRRMS). There is, however, a knowledge gap as to which type of DMT people prefer, how their choices are related to treatment attributes (how aggressive they are, risks, mode of administration, etc.), and how these preferences relate to when/if treatments are started. Discrete choice experiments (DCEs) help to understand the relative importance of treatment attributes and the trade-offs made in decision-making but they need to be supported by robust qualitative work.

Aim: To identify which are the attributes of DMTs attributes most important to PwRRMS as a first step to design a DCE.

Methods: Attribute identification included 3 phases:
1) A critical review of the literature to generate a conceptual framework for setting out the underlying context in which behavioural decision making takes place.
2) Stakeholder focus groups (n=17 participants) with PwRRMS, neurologists and MS nurses to explore preferences for individual DMTs, their benefits and risks, and to establish a sampling strategy.
3) Semi-structured qualitative interviews with PwRRMS (n=30) to understand the main factors that discourage and encourage choosing, starting, switching and stopping DMTs; why such decisions are taken, and how specific preferences relate to attributes of the DMTs. Data was analysed using a thematic analysis.

Results: Eight key interrelated attributes of DMTs were identified:
1) mode of administration;
2) effectiveness;
3) duration, severity, controllability and reversibility of side effects;
4) how treatment routine - including frequency of administration and side effects management- fits into lifestyle;
5) practicality & transportability;
6) treatment monitoring;
7) likelihood of adherence;
8) parenthood and reproduction.

Conclusion: PwRRMS trade off a complex set of interrelated attributes to weigh up advantages and disadvantages of DMTs. Some of them are related to DMT clinical outcomes (efficacy, side effects) whilst others are related to how DMT outcomes and processes can be integrated into patients' lives.

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